
ADVANCING THE COMMUNITY-DRIVEN RESEARCH AGENDA

Conference Report

National Institute of Environmental Health Sciences
Environmental Justice & Community-Based Prevention/Intervention Research
Grantee Meeting

Research Triangle Park, North Carolina
October 27–29 1997

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Environmental Health Sciences

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I. INTRODUCTION

Communities in the United States are routinely exposed to environmental health hazards, ranging from the toxic chemicals that farmers encounter in the fields, to the radiation that reaches communities downwind of a nuclear test site. In many cases, little is known about the extent to which these communities and individuals have been contaminated, or about the health problems they have incurred.

Disproportionate exposure to environmental health hazards in historically underserved and disenfranchised communities is an environmental justice issue. Environmental health based on principles of justice requires access for all to good medical care, a sound scientific knowledge base for environmental improvement, and attention to socioeconomic and racial inequalities. In this regard, scientific knowledge is underdeveloped, and many research professionals are not familiar with problems faced by the poor and people of color.

The prevention of environmentally related health problems requires innovative research and solutions. To this end, the National Institute of Environmental Health Sciences (NIEHS) has developed a series of research programs over the last five years. Two such programs under the auspices of the NIEHS translational research activities are the Environmental Justice program and the Community-Based Prevention/Intervention Research program. These programs seek to apply fundamental research findings directly to public health, translate results easily to the public, and include mechanisms for involving the public in the identification and investigation of environmental health concerns.

The primary objective of the Environmental Justice (EJ) program is to establish methods for linking communities directly affected by adverse environmental conditions to researchers and health care providers. By developing effective modes of communication, the program promotes community participation with researchers and health care providers

to develop responses and to set priorities for intervention strategies. The long-term goal of the program is to provide high quality research that addresses the environmental health concerns of the communities involved. Twelve such projects are currently funded.

The Community-Based Prevention/Intervention Research (CBPIR) program, initiated shortly after the EJ program was underway, seeks to expand scientific knowledge and understanding of the potential causes and remedies of environmentally related health disorders. At the same time, it aims to enhance the capacity of communities—particularly disadvantaged or underserved communities—to participate in the processes that shape research approaches and intervention strategies. Nine such projects are underway.

"Advancing the Community-Driven Research Agenda," 27–29 October 1997, was the first conference to bring together grantees from both the EJ and CBPIR programs. Its purpose was to allow grantees and program directors to explore the effectiveness of the programs, and to allow grantees to share their experiences with collaborative research. Conference participants included ethnically and racially diverse members of three primary constituencies: health care providers from government agencies and independent organizations; research scientists, primarily from universities; and members of community-based organizations from regions as varied as the Northern Territories of rural Alaska, to members of urban neighborhoods in West Harlem, New York. These participants from extremely diverse backgrounds and experiences were united by the NIEHS mission to prevent environmentally related health problems.

Many participants posed questions about the collaborative research process. One participant commented that, while there were many people present at the conference who could respond to specific research-related questions, participants were their own teachers when questions were raised about community participation in science. Community-based

research (research conducted with the participation of community members), although certainly not a novel idea, is still cutting-edge.

By definition, community-based research includes an action component, thus distinguishing itself from more traditional, basic science, which is not directly connected to the community. Improvements in health and living conditions are a priority for most community-based organizations, as is the power to make their own decisions and to take actions to protect their health. The initiatives of the NIEHS translational research programs reflect the need for science that responds to community concerns, while reflecting the need for science that benefits from community expertise and “indigenous knowledge.” During the conference participants collaborated to define the importance of the work, emerging, in the end, with a description of the research model and with specific, tangible recommendations for the NIEHS and the scientific community.

This report contains a summary of themes identified in formal breakout sessions and informal conversations throughout the conference, complemented by actual notes and documents written by participants. The NIEHS-sponsored conference on “Advancing the Community-Driven Research Agenda” was the first of its kind. Many participants expressed a desire that future workshops be held, in order for them to expand their capacity to conduct community-based environmental health research and education, while garnering further understanding of the complex interrelationships among pollution, poverty, and health status.



II. NARRATIVE

Leading Up to the Conference

The NIEHS strives to reduce the burden of human illness and dysfunction from environmental causes through a multidisciplinary biomedical research program, prevention and intervention efforts, and a communication strategy that encompasses training, education, technology transfer, and community outreach. Because of the desire of the public for research about health risks of exposure to physical and chemical agents, NIEHS is playing an increasingly important role in numerous public health issues.

Although governments, industries and members of the public are challenged daily to make decisions about environmental health risks, there have been few programs developed to help prepare the public to meet this challenge. Prevention of environmental health problems does not merely require public education; it also requires innovative research to develop solutions, training of scientists and health care providers, and creation of opportunities for environmental health science careers. Therefore, it is critical that while the public is being educated about health issues, it is also involved in the identification and investigation of environmental health concerns.

Over the last five years, the NIEHS has developed translational research programs to help address environmental public health issues. The Institute's activities share the following objectives:

- To improve understanding of how environmental factors affect human health.
- To develop better means of preventing environmentally related health problems.
- To promote partnerships among scientists, health care providers, and community members.

NIEHS translational research activities include environmental health science educa-

tion, NIEHS Center Community Outreach and Education, Environmental Justice, and Community-Based Prevention/Intervention Research.

"Advancing the Community-Driven Research Agenda" brought together grantees from both the Environmental Justice and Community-Based Prevention/Intervention Research grant programs for the first time under NIEHS auspices; it was also the first NIEHS-sponsored meeting since 1994 to address specifically environmental justice and community-based research. For these reasons, the conference represented a significant opportunity for the assessment of the past, present, and future of community-driven research and of the role that NIEHS can play in this field.

In addition to grantees and their project teams, a number of invited guest speakers, representatives from federal agencies and non-governmental organizations, and others interested in community-based research in environmental health science attended the workshop. By bringing together a diverse group of people with differing backgrounds and areas of expertise, the conference marked an important occasion in the development of NIEHS programs in public health and translational research. It provided an opportunity to explore community-driven research in environmental health science and to plan collaborations, coordination, and future directions.



Jerry Phelps, Walter Handy, Linda Silka, Norman Anderson

Tour of Environmental Justice Grant Site, Tillery, North Carolina

Early Sunday morning, October 26, 1997, conference participants gathered in the lobby of the Omni Durham Hotel. For many, who had traveled through the night from as far away as California, Massachusetts and Ohio, this was their first visit to North. Steve Wing, from the University of North Carolina School of Public Health, met participants and guided them onto a bus. Soon, the tour bus was out of the metropolitan college-town of Durham, heading through corn and cotton fields to a part of the South that many had read about in history books but had never seen. By mid-morning, conference participants had reached Halifax, NC. Hazy skies had turned to rain, and Gary Grant, Executive Director of Concerned Citizens of Tillery, ran in from the rain to greet participants on the bus. A narrated tour of the town, seat of government of Halifax County, began. M.L. Tanner, environmental health educator, hosted a welcoming session at the county health department, during which participants learned of an African American neighborhood that has been excluded from local sewer service. Then, participants toured the Halifax history museum, an industrial hog growing facility in the county, and the "Remembering Tillery" historic photo exhibit.

Southeast Halifax county (i.e., the Tillery area) is the site of an NIEHS Environmental Justice grant that brings together the Concerned Citizens of Tillery, the Halifax County Health Department, and environmen-

tal health scientists from the University of North Carolina School of Public Health. The Tillery area is 98 percent African American, and the rapid growth of corporate hog production in this community has become a major environmental justice concern. As participants on the trip learned from experience, industrial hog operations smell bad, but of greater concern, the hogs in eastern NC produce more than twice as much raw sewage as the entire state's population.

Exclusion of African American communities, such as Tillery, from water and sewer services has been identified as an important environmental justice issue. Most residents depend on wells for drinking water, and groundwater and wells near such large hog operations have been found to be contaminated with high levels of nitrate. Participants on the tour also bore witness to the loss of land to industrial farms and the lack of health care and clean drinking water.

After the tour, participants gathered at the Tillery Community Center for a southern Sunday supper of chicken, beans and salad, with their choice of peach or berry cobbler for dessert. People of all ages, from infants to the oldest woman in Tillery and proud mother of 20 children, took part in what grew to be a celebration of hope. As participants had their meal and afterward, they listened to speeches about the environmental health of Tillery and the dignity of communities suffering from environmental injustice. Marcus Tillery, an engineering professor at North Carolina A&T University, whose ancestors once toiled as



slaves on the 6,000 acre Tillery Plantation, exhorted researchers to use their talents in the struggle for environmental justice. After much prayer and song, the bus filled again and participants headed back to Durham.

Conference Proceedings

On Monday morning, conference participants met at the NIEHS facility in Research Triangle Park, NC, a large building with a



Gary Redding, Shauna F. Jones, Kenneth Olden, David Woodley, Gary R. Grant

view, through the glass walls of the ground floor lobby, of a pristine, man-made lake. The meeting rooms, hallways, cafeteria and outside picnic tables by the lake served to facilitate many open and frank conversations among participants over the next three days.

Opening remarks were made by Allen Dearth, Program Administrator for translational research at the NIEHS, Kenneth Olden, Director of the NIEHS, and Norman Anderson, Director of the Office of Behavioral

and Social Science Research (OBSSR) within the Office of the Director, National Institute of Health. NIH leaders described how issues of environmental justice and community-oriented research relate to scientific activities and the missions of the NIEHS and OBSSR.

The opening plenary session focused on the presentation of the following three successful community-university partnerships: a North Carolina environmental justice project, presented by Gary Grant, Concerned Citizens of Tillery, and Steve Wing, University of North Carolina; environmental justice and community-based research in Northern Manhattan, presented by Peggy Shepard, West Harlem Environmental Action, and Joe Graziano, Columbia University; and the Akwesasne environmental communication program, presented by Katsi Cook, Cornell University, and David Carpenter, SUNY Albany. This session addressed what communities facing environmental hazards can expect from scientists and what scientists can offer community residents. Discussions addressed barriers and incentives to community-scientist partnerships, a framework for establishing successful working relationships and the importance of setting a scientific agenda that addresses community concerns. Examples were presented to demonstrate how community input could lead to successful research projects for all involved.

During the afternoon, participants worked in breakout sessions, discussing topics which included the following: scientific research needs related to environmental justice; incentives and barriers to research collaboration;



and reducing risks from environmental hazards. These sessions gave participants the opportunity to discuss issues of concern in a smaller group setting. Discussions addressed examples of the following: how research questions have been asked and answered through work for environmental justice; barriers to communication and cooperation and strategies to overcome these; and education about avoiding hazards in the context of the more fundamental goal of creating a healthy environment.

Between sessions, in the halls, over lunch in the cafeteria and on the bus back to the hotel, participants introduced themselves. The new faces, which at first had seemed overwhelming, were familiar by evening. Monday night there was a warm reception at the Carolina Theater in Durham, a recently renovated Vaudeville-era hall originally built for whites, and desegregated in the 1960s.



David Carpenter, Katsi Cook, Anne Sassaman

On Tuesday morning, a panel session discussed how to make research relevant to communities and health care providers. Participants talked about how community and health care goals relate to scientific goals of producing knowledge.

A second breakout session that morning addressed approaches related to advancing the agenda of community-driven research: defining goals and how they are met; and lessons learned from ongoing EJ and CBPIR projects.

Participants discussed the following important questions:

- What are the goals for environmental justice and community-based research?
- Do community-based projects meet the goals that have been set for them?
- What lessons have been learned from this work to date?
- What works well?
- What may not work well?
- What have we learned from our successes and failures?

During lunch, conference participants had an opportunity to view and discuss posters from all EJ and CBPIR projects. This enabled all involved to talk in more detail about specific projects, while also allowing them to form closer connections for future collaborations and networking.



Joe Graziano, Charles Lee

In the afternoon, some participants expressed a desire to meet separately with their colleagues, so breakout sessions were gathered in three groups, representing community-based organizations, health care providers, and environmental health scientists. In each breakout group, participants stepped forward to

facilitate discussion. Conversation was often impassioned, as participants from all perspectives struggled with the theme of this session: identifying questions for advancing community-driven research. This time was critical, for it allowed each group to brainstorm regarding incentives and barriers to collaboration, while offering an opportunity for them to raise issues that had not surfaced in other settings.



Allen Dearry, Norman Anderson

Participants remained animated well into the late afternoon for this day's final breakout session, addressing how, exactly, to advance the community-driven research agenda in an increasingly competitive, entrepreneurial research environment, while maintaining values of scientific integrity and social justice. On this subject, the notes from one of the small group sessions may be instructive (see Appendix). Differing groups reached many similar conclusions during the meeting.

A volunteer Synthesis Committee, comprised of members from each breakout session, met Tuesday evening to review, compile and prepare to present the findings of the smaller groups in a cohesive manner.¹ Participants described the late night session, which lasted until midnight for some, as exciting, with good participation by all members and strong agreement in favor of the outcomes.

¹Members of the Synthesis Committee included: Michael Belliveau, Communities for a Better Environment; Katie Brown, University of Cincinnati; Gary Grant, Concerned Citizens of Tillery; Pauletta Hansel, Urban Appalachian Council; Charles Lee, United Church Commission for Racial Justice; Lorette Picciano, Rural Coalition/Coalition Rural; Peggy Shepard, West Harlem Environmental ACTION.

Development of an Action Plan

On Wednesday morning, the Synthesis Committee presented an overview of its deliberations to the conference as a whole. Research questions, a model for community-driven research, and recommendations to the NIEHS were presented and discussed.

Given the previous day's events, participants were eager to hear the synthesis. Discussion was open to the floor, resulting in several suggestions that were incorporated into the synthesis. Participants supported recommendations such as developing a "code of ethics" and principles of collaboration for community-based research. Participants also expressed the hope that the NIEHS will continue to expand its support of this cutting-edge research. By noon, participants began to leave for their buses to the airport. Although conversation could have continued well into the afternoon, the conference ended on a high note with individuals looking forward to seeing their work through.



III. THEMES AND OUTCOMES

1. ACCESS TO SCIENCE BY COMMUNITIES

"Science has historically been 'Me PI, you peon'. We are trying to find an equitable approach to solve our environmental health problems."

—Katsi Cook, Akwesasne, Mohawk Nation and Cornell University

Communities often discover their problems but lack the scientific expertise to validate their concerns. The Woburn case, described by Gretchen Latowsky in her presentation, demonstrates this. Alarming numbers of children in Woburn suffered from leukemia. Families of affected children were sure the leukemia was the result of a contaminated water supply. Although officials would acknowledge the elevated incidence of childhood leukemia in Woburn, they did not take action, claiming that no information indicated contaminants existed during the time of the elevated incidence of leukemia. The community members organizing around this problem had a difficult time locating sympathetic researchers who would listen to their concerns and conduct sufficient research. Eventually, they located scientists at an NIEHS Center in Boston, whose final study concluded there was a "positive statistical correlation" between the outbreaks of childhood leukemia and exposure to water.

Community representatives at the conference confirmed the need for access to scientists who will help them define problems they have identified and articulate research questions. After questions are formulated, communities need "trustworthy" and "honest" technical assistance providers—specifically within universities and other research institutions—to help conduct the research. Participants mentioned the need for extension agents at Land Grant Universities, to assist in identifying the source of environmental problems through collaborative research.

Community representatives identified a need for science that empowers communities and provides results to be used in support of

sustainable change. Communities need researchers who can provide assistance evaluating how research results are used toward this end. The following primary mechanisms were identified to help improve access to science by communities:

- An organization or system to inform communities whom in a university is doing research that addresses their concerns.
- More time allotted to faculty by universities for their work with communities.
- The provision of ongoing technical assistance and expert testimony by scientists and health professionals.
- A group or network with access to an interdisciplinary team of researchers to act as "matchmakers," helping connect scientists with communities in need.

Community representatives at the conference confirmed the need for access to scientists who will help them define problems they have identified and articulate research questions.

2. ACCESS TO COMMUNITIES BY SCIENTISTS & HEALTH CARE PROVIDERS

"We community people want help and change when researchers come into the community. We're waiting for the researchers to catch up with what we know." —Beverly Jackson, St. Regis Mohawk Tribe Health Services

Scientists and health care providers working on environmentally related health problems need human populations. To investigate the effects of single and multiple exposures, scientists

study communities that have been exposed to agents of disease. Scientists often seek a community with which to work, having already identified a research problem. Unfortunately, in many cases scientists and health care practitioners find that both professional institutions and communities present barriers to such a process. Often scientists and health practitioners find their desire to work in communities is not appreciated by their institution. Tenure and promotion standards frequently do not recognize community-based work, and there are few institutional incentives for scientists to work with communities.

When a scientist is seeking a community with which to work, the barriers s/he experiences at the community level have to do with trust, language and culture. The traditional process of seeking a community with which to work was referred to negatively during the conference by Yolanda Banks-Anderson, North Carolina Central University, as “community shopping.” This label reflected the isolation from communities that scientists often feel, as well as some negative experiences with scientists by communities. However, the rewards for conducting a collaborative project are plentiful.

Scientists at the conference acknowledged that communities can act as the social conscience of the scientists, and that the personal rewards are often greater than any resulting publication. Once the project is successfully completed, scientists often find the support of grassroots organizations and community groups critical to the process of influencing decisions in their institutions regarding community-based research. Participants made several suggestions to improve access to communities by scientists and health care providers:

- Scientists and health care providers should not “parachute into communities,” but rather spend significant time learning about the community, about the issues of concern and the political context in which the community is functioning. Scientists should also make the community feel like they are being

Often scientists and health practitioners find their desire to work in communities is not appreciated by their institution.

heard, and relationships should be established before research begins.

- Communities, scientists and health care providers should work together to ensure that tenure and promotion standards at research institutions are changed to reward community-based research.
- Where health care providers and scientists feel their institution is not supporting their work, it helps to refer to the public minded mission of the institution and remind them that this mission is not being fulfilled.
- The community organization should be the lead institution or should be invited to participate in the grant writing process as a “co-investigator.”

3. SCIENTIFIC RESEARCH NEEDS

Central to the debate on environmental justice is the view that the study and development of standards used to address health hazards at the community level has been largely ignored for the following two reasons: poor communities and people of color—who experience the most significant concentrations of potentially hazardous compounds—have less access to political power, money and resources to prevent pollution than high income communities; in communities of poor people and people of color, health hazards are often multiple and compounded—one good industrial operation may attract another—due to the dearth of health promotion and protection programs in the community.

In short, EJ research is more complex than traditional forms of research. In many cases, few people have health records, and populations are small or difficult to define. The participants, through the synthesis committee, articulated the following research questions related to environmental justice research:

- How should long term effects of chronic exposures be examined?
- How should health care providers be effectively trained about environmental risks and exposures?
- What risks are associated with multiple/synergistic effects of environmental exposures?
- How should surveillance systems be implemented to monitor less severe symptoms?
- How can changing health delivery systems effectively address environmental health?
- How can existing data sets be linked to document associations between exposures and health outcomes?
- How can interventions address the role of socioeconomic conditions on health?
- How can data in hospitals and other medical establishments be made accessible to communities?
- How can more surveillance systems be established to document cases of asthma and problems coming to health care providers and clinics?
- How might clusters of exposure and/or low levels of exposure be addressed?
- How can risk assessment be democratized so that communities participate more in this process?
- Finally, what is the interrelationship among social, economic, and institutional factors, pollution, and health status? This is the basic question that EJ and CBPIR programs have

been designed to address, and more research and education efforts such as these are needed to examine these issues more thoroughly.

4. COMMUNICATION AND CULTURAL SENSITIVITY AMONG COLLABORATORS

"I am not familiar with the jargon of the medical field. I take care of people." —Beverly Jackson

Discussions at the NIEHS conference confirmed that consistent and open communication between all participants is essential to the success of collaborative research projects. Communication is especially important in the following two instances:

- When community members have never worked with scientists, and are, therefore, unfamiliar with the institutional process.
- When scientists have little or no background working with communities in struggles for environmental justice.

Traditional methods used by scientists to convey findings, such as slides and overheads, have been found to be ineffective in some community settings.

Participants described "two-way cultural sensitivity" as a means to successful communication.

Community members need to recognize the background and culture of researchers and health care providers. Likewise, researchers and health care providers need to be sensitive to the culture of the community members with whom they are working.

Effect communication is often hampered by problems related specifically to language. Even

in cultures that speak the same language, words often carry different meanings—particularly when there are geographic dialects. Words used incorrectly can make people feel disempowered; and often, they significantly harm a relationship. When doing cross-cultural research, it is critical for researchers to be aware of how words are being used, and for them to listen attentively as others are speaking. Storytelling, for instance, is sometimes used to convey important information, but tends to evoke frustration on the part of those who are not accustomed to such communication. During the conference, there was agreement that health care providers, in particular, should not presume they know the condition of a patient until they have listened to the entire situation as presented by the patient.

When researchers report their findings to communities, they run the risk of using culturally inappropriate methods. Traditional methods used by scientists to convey findings, such as slides and overheads, have been found to be ineffective in some community settings. Community events, such as a local high school performance illustrating the hazards of a toxic dump, have been found to work well to convey results.

Participants shared experiences of the kind of miscommunication that can result from scientists and health care providers not being aware that families have mixed languages and different levels of proficiency in addition to varying levels of literacy. It was recommended that translators and “back translation” be used, whenever necessary during the research, to ensure that each party be understood correctly and understand correctly. To this same end, it was also suggested that scientists avoid using jargon.

Finally, it was suggested that scientists researching data on environmental health problems make a special effort to learn from health care providers exactly how data have been recorded. Data in clinics are organized in such a way that researchers often cannot understand them until they have spoken with the nurse practitioners or the physician assis-

tant who actually recorded the data. If researchers speak only with medical directors, they may be unaware of how data are coded.

Participants made the following suggestions to assist scientists, health care providers and communities in their communication:

- That adequate time be allotted in a grant period to overcome communication barriers.
- That training be provided to communities on the basic terminology used in the research process.
- That regular forums be scheduled to update the public on progress in lay terms.
- That a third party be engaged in negotiations to bridge the gap between communities and scientists.
- That scientists take a course to learn how to communicate effectively with communities.
- That all remember Respect, Equity and Empowerment.

5. RESEARCH DESIGN & TIME

“After four years we are beginning to feel comfortable working together. It isn’t enough time to build relationships.”—Dianne Quigley, Childhood Cancer Research Institute

Perhaps no groups struggle more for time than do scientists, grassroots organizers and health care providers—particularly those affiliated with universities. Inevitably, time—and its role in the research process—was a major topic of discussion. Short-term, community-based studies lead to distrust and frustration on the parts of both researchers and communities. The Environmental Justice and the Community-Based Prevention/Intervention Research grants are supported for four years. Even that is not quite enough, though, for the process of building partnerships on a foundation of trust is a “long haul.” Continuity and long-term research partnerships are more

favorable than are short-term partnerships—usually dictated by grant periods.

On the topic of time, participants also reiterated the particular complexity of environmental justice research. Health care providers, who spoke eloquently on the issue, shared the view that EJ research must grapple with research designs and methods that need additional time to examine multiple and cumulative exposures, synergistic effects and small or isolated populations.

When those involved are rushed, relationships are compromised. According to participants, a research relationship not based on trust and mutual understanding leads to unsound science. The community might, for example, withhold critical information. Moreover, the concerns that led to the research process may not be addressed.

Participants suggested that grants support a process by which communities, particularly underserved communities, explore and express their concerns at the beginning of the relationship through appropriate forums, as is commonly done in existing NIEHS-supported EJ grants. Furthermore, they suggested that collaborators take time to identify local institutions to assist with the process. Communities need research that does not alienate or supersede an existing community infrastructure, but, rather, lends to its success and capacity to respond to research needs (i.e., strengthens institutions and builds alliances).

Discussion on increasing the time allotted for community-driven research resulted in the following recommendations:

- That the communication process be evaluated as a research activity, which is the case in the NIEHS EJ program.
- That mechanisms be in place at the beginning of the process to deal with issues not yet resolved at the end of a grant award.

According to participants, a research relationship not based on trust and mutual understanding leads to unsound science. The community might, for example, withhold critical information.

- That adequate time be allotted to disseminate results to the community for their response throughout the research process.
- That scientists without a relationship to a community be granted time to develop relationships with a community and to explore how a community's needs can be met through research.

That the time it takes to examine the combined effects of multiple agents be considered in the design of the research process.

6. SETTING RESEARCH GOALS

"Let's change the 'show me the science' paradigm and take action before it is too late"

—Anonymous Participant

The ultimate goal of NIH grant support is to improve public health. There was a feeling among participants that some researchers sometimes tend to lose sight of this goal, in light of new scientific discoveries. Participants acknowledged that there are significant cultural differences in people's ideas of "public health." In turn, the differing health research goals of community residents, clinicians and academicians may be a source of conflict.

In traditional grants, research goals are seldom even discussed outside of a close circle of academic associates, much less with all stakeholders. When such goals are discussed, each party (or stakeholder) approaches discussions/negotiations from a "powerbased" or

“positional” standpoint. That is, each party offers its goals as the (one and only) solution to the negotiation. During the course of negotiations, it is typical that each party expends considerable energy defending its solution against the attacks of the other parties.

Conference participants offered “interest-based” or “principle-based” negotiations as an alternative to this strategy of establishing health research goals. Interestbased negotiations operate on a consensus model. Through this process, parties are often able to identify many mutual interests. The process requires that a large pool of options be formulated to address listed interests. Options selected from this pool, then, will address the interests of all parties. Recommended courses of action (e.g., health research goals) are constantly improved, because preserving the relationship among the parties is more important than any single decision that the group makes, and is more important than any single interest or concern of the parties.

Participants suggested the following to aid in defining research goals:

- Scientists should communicate at the beginning what has led to their research and what kind of measurable goals will be sought.
- Communities should communicate their needs (both political and scientific) to scientists and health care providers at the beginning. Such expressions of interests and ultimate negotiations may serve as the basis of written agreements, contracts or covenants among the parties as to how the research or consultational relationship will work.

7. INTERVENTION AND RISK ASSESSMENT ALTERNATIVES

“Schools of public health traditionally study factors that cause disease, but they don’t do a damn thing about them.” —David O. Carpenter, State University of New York

Steve Wing, who organized and facilitated the session on reducing risks and developing

strategies for avoiding hazards, said the workshop was “turned upside down” when community representatives asked the question, “Who is supposed to change their behavior, community members or corporate and government institutions?”

“Advancing the Community-Driven Research Agenda was the first NIEHS grantee meeting to include both the EJ and CBPIR grantees. Intervention was a key area of consideration. Communities recommended that the parameters of inquiry be expanded. In their view, it made little sense to employ resources to help a population adapt to a toxic hazard, when it would be best to remove the hazard. Thus, any model of intervention and risk reduction needs to interface with corporate and political entities, even if it takes formulating creative incentives for them to be involved. There was a consensus that any strategy of intervention must balance the perspectives of the public health community with that of the grassroots community.

Community partners tend particularly to distrust risk assessment, if government agencies are involved.

Regarding traditional risk assessment processes, participants offered several observations that may—if taken into consideration—create a foundation for an “alternative risk assessment.” For starters, a precautionary approach may be taken, whereby intervention takes place before the weight of evidence is conclusive. The precautionary principle supports taking preventative measures when there is reasonable evidence of a causal relationship between an agent and disease, rather than waiting until the causal relationship can be proven. For example, scientists recommended expanding standards of significance for research. They noted that responsive and

well-designed research could address not merely evidence for a causal relationship, but also, criteria for action. Thus, sometimes scientists could stand with communities and say, “We have found enough to say that conditions warrant immediate intervention to protect health.”

As a result of feeling excluded from traditional risk assessment dictated by the scientific method, some community partners expressed a general distrust of scientists. Community partners tend particularly to distrust risk assessment, if government agencies are involved. “Safety levels” determined by these outside parties are, for the most part, thought “suspect” by communities. Consequently, models of assessment that include community participation and community training should be supported.

In addition to lending to the sustainable capacity of the community, involving residents in the risk assessment process will ultimately create a healthier environment. According to participants, communities in the face of a health risk sometimes live in denial. Often the cause for this denial is that the economic base of the community may be dependent upon the source of the risk (e.g., a factory, plant, power facility). With community participation at all stages of the process, there will be little room for denial. If community members help acquire the information, they will be in a position to instigate sustainable change, such as clean industry rather than no industry. If community members are involved, the results of collaborative research may help produce enforceable standards and may influence policy and law.

The endorsement of an alternative risk assessment process that includes community participants was suggested, but with the roles of all players and distribution of resources clearly defined, and an estimate of the time needed to conduct the assessment. When applying for funding for risk assessment, the holding of community forums was suggested, so that the environmental issues might be identified, as they exist from the community

perspective, with various social and cultural risk assessment needs taken into consideration. Finally, it was expressed that scientists need to be honest about what they do not know and particularly about the limitations of science. The following changes were recommended:

- Improvement of assessment tools and measures to address cumulative risks and exposures, multiple exposures, and clusters of exposure and health concerns in populations of more limited size.
- Further examination of the interrelationship of a myriad of factors—including social, economic, and institutional—in conjunction with assessment of pollution levels.
- The inclusion, in new risk assessment methods, of the surveillance of more factors, including generalized symptoms and less severe symptoms and the implementation of new standards of significance.
- The inclusion, in behavioral change outcomes, of changes by institutions and structures—not merely those by individuals and communities.
- The development of criteria for action at the outset of research in addition to criteria for causation.
- Community-based risk assessment, in which community members participate directly in the evaluation process.
- The involvement of communities in risk communication.

8. ACCOUNTABILITY

“...academics are frequently accountable to the University administration rather than to the community and...guided by project funding over community needs.”—Lukata Mjumbe, African American Environmental Justice Network

The word “accountability” was used throughout the conference to describe the type

of relationship that should exist between scientists and communities, as well as that between health care providers and the community. Many participants felt that research conducted in response to the community-driven research agenda should be accountable to the community at every phase. The following suggestions were made to increase accountability:

- That university faculty and communities submit proposals to each other before submission to a funding agency.
- That community-appointed advisory boards be established, in order for community members to provide input to decisions at all phases of the research, and so that they may help set priorities for the research and provide regular feedback.
- That programs be established to train community members to work as members of research teams.
- That there be contracts or guidelines setting the terms and conditions for researchers by the community before the research process begins.

9. FUNDING AND ALLOCATION OF RESOURCES

"We are talking about an absolutely revolutionary concept here—allowing communities to have control of research monies and ownership of data."

—Chris Peterson Brus, *The University of Iowa*

All participants at the NIEHS conference were intimately familiar with the need for funding. Whether the need stemmed from a life-long pursuit of research in a particular field, or from living in a hazardous environment day in and day out, all participants recognized the rarity of programs, such as the NIEHS Translational Environmental Health Research programs. For many participants, discussion on the topic of funding at the NIEHS is a sensitive area. For community-based organizations that have struggled to gain access to scientific expertise in a collaborative

research process, there are few alternatives. The institutionalization of such collaborations is tenuous at best. On the one hand, community-based organizations are hesitant to criticize the process, at the risk of losing access to science. On the other hand, if the collaborative process is not institutionalized and research processes are not adjusted to reflect accurately the concerns of community-based organizations, communities may find themselves involved in traditional scientific research where, sadly, the community is more often the subject than the collaborator.

An issue voiced in many of the workshops and plenary sessions was the need for collaborative research grants—where partnerships are required and funded equitably. It was suggested that the community be considered a "co-investigator" and that grants be subcontracted directly to the community-based organization. This process would allow communities active participation in the allocation of funds to ensure the community-driven research agenda.

Presently, representatives of community-based organizations feel they are not, in most cases, adequately compensated for their time; they feel, moreover, that a discrepancy in pay and respect exists between university, hospital, and government agency personnel working on a grant, and community members. They also expressed their concern that adequate funding is not allocated to sustain a research infrastructure—or access to science—that will remain once the grant period has ended. Community participants see the magnitude of overhead assessed by universities as another aspect of the inequality between partner institutions.

It was strongly suggested that planning time be funded by grant-making institutions. This would be particularly advantageous to scientists who are not actively involved with a community when a Request for Applications is announced. A planning grant, or significant period of time between an RFA announcement and the due date, would enable scientists to become familiar with the concerns of a particular community where there is potential for

research. Time, particularly funded time, would be advantageous to communities, if they had the opportunity to seek responsive scientists who would help them define precisely what research questions would address their needs. Finally, it was stated clearly that an over reliance on funding tends to make less of the partnership, especially when the funding is gone. The ideal research partnership will not be driven by funding, but rather will be enhanced and greatly improved by adequate funding. Other recommendations included the following:

- That participatory research and community-university partnerships be supported to define environmental health problems and implement research and prevention approaches.
- That funding be contingent upon collaboration between communities and researchers.
- That EJ and CBPIR research programs be continued and expanded.
- That other research programs (e.g., risk assessment and communication) be funded via community-based partnerships.
- That small grants or planning grants be used to initiate university-community collaborations.

10. AREAS FOR FUTURE ATTENTION

The following topics have been identified as ripe for discussion at future meetings:

a) Science Lite. EJ grantees saw the CBPIR program as, primarily, a somewhat more rigorous scientific approach, but also as a compromise. Some scientific partners thought that the EJ program is viewed as less substantive, i.e., “science lite.” Nevertheless, the EJ grantees as a group affirmed their dedication to building new research standards within the EJ and CBPIR programs. EJ grantees also recognized that CBPIR grantees brought the perspective and stronger involvement of health care providers. The issue of “science lite” and defi-

nitions of successful research in both programs will require closer examination in the future.

b) Definition of Community. A central question raised during the conference was, “How is community defined?” Conversation indicated that, particularly among the newer CBPIR grantees, the definition of community—and terms of community participation—might differ from those held by some EJ grantees. The perception of CBPIR grantees toward partnership seemed to include the view that scientists could play an organizing role in a less organized “community” without access to any other “help.” In other words, the presence of scientists—and a scientific agenda—would actually be a catalyst for community organizing rather than a response to community organizing. Some participants were skeptical of this model, on the grounds that it encourages scientists to engage in “community shopping,” to improve funding potential rather than to exert the long-term effort to create sustainable partnerships. In this scenario, a relatively powerless community with little organized voice might be more appealing to scientists than a more organized and potentially contentious community. A common understanding of how the term “community” is used in the grant process will improve research design and collaboration.

c) Peer Review Panels. The decision by NIEHS to broaden EJ grant peer review panels to include community representatives was critical to the multidisciplinary character of the program. NIEHS invited diverse community representatives to participate with scientists and health care providers in the peer review process. Participants in the panels developed a level of mutual respect that continues to inform the EJ process.

Thus far, the idea of including community partners on additional scientific review panels has not been implemented at NIEHS or elsewhere. No structure similar in composition to the review panels has emerged among the grantees to serve as a vehicle to support or design more collaborative research, or to develop and nurture ongoing partnerships.

However, a clear result of this collaboration on review panels is that standards and expectations are increasing. A cadre of new collaborators poised for future research partnerships is growing. Participants felt that the NIEHS deserved significant credit for this groundbreaking effort.

d) Expectations. After nearly four years of work, communities were testing whether they really were considered partners in research with something valuable to share. To what degree has mutual respect developed among all partners? Can they see the work in which they are engaged as a joint enterprise that will expand limits and meet community and scientific standards? Will scientists be willing to state their goals more openly, and communities willing to understand and accept their expectations for their project with respect to the institutions that employ them? Participants proposed that a discussion on the clarification of such expectations would be an excellent endeavor for the next meeting.

e) Evaluation. There remains a need to consider more fully how to evaluate the effectiveness and success of programs, such as EJ and CBPIR, that involve significant community participation and that have an education and communication focus as well as a research and intervention focus. Proposed measures include more qualitative transformations, such as:

- Increased capacity within the community. Is the community more mobilized, aware of environmental health issues, proactive, able to define its own issues, and able to participate equally with providers and scientists?
- Leveraging. Does this early-stage support enable such partnerships to move forward and obtain additional funding for further efforts?
- Sustainability. A three-way structure is admittedly difficult to maintain. However, a longer-term impact is necessary to affect change. How does this work produce a sus-

A cadre of new collaborators poised for future research partnerships is growing. Participants felt that the NIEHS deserved significant credit for this groundbreaking effort.

tainable, continuous influence on communities, providers, and scientists?

- Tools. Are useful methods, e.g., Geographic Information Systems developed and implemented?
- Policy or system change. Do these projects enable communities to develop power-sharing relationships with not only scientific and health care partners but also with others in government and the business community?
- Impact on the field. What overall outcome or result related to environmental health science, community-based education and research, or intervention approaches can be regarded as the aftermath of a given project? What is the major accomplishment?

Although such issues were discussed, more attention needs to be given to specific criteria for evaluating success of translational environmental health research programs.



IV. COMMUNITY DRIVEN RESEARCH MODEL

What emerged from the discussions and was presented in the final plenaries was a comprehensive description of the community-driven research model. The process would involve collaboration of existing partners with new ones, and transference of skills to inform new collaborations. Participants agreed, “NIEHS and its partners should develop, describe, test, evaluate and market this model to other institutes and other federal agencies.”

This collaborative model:

- Begins with the **goals and questions** of the community.
- Is **participatory** at every level.
- Is **multidisciplinary**, and **requires respect** for the knowledge of all partners.
- Includes as community partners community-based groups who are accountable representatives of the community.
- Develops **codes of ethics** defined by communities and their partners.
- Develops **principles of collaboration** that ensure accountability of all partners.
- Is **culturally sensitive** and uses a diversity of communication tools and appropriate language.
- Involves **sharing of power**, including the sharing of significant levels of resources with the communities.
- Attempts to build a **common language** among partners.
- Develops and employs **new standards for evaluation of evidence** including:
 - Criteria for causation
 - Criteria for action
- Addresses more complex and difficult-to-study questions that are often overlooked.
- Develops a more collaborative and broader definition of problems with preliminary descriptive studies.
- Creates **alternatives in research design and intervention**, and active consideration of which options are most important and provide the most value for resources used, in light of the goals of the community.
- Assembles an **appropriate team of research partners** who are most essential to the success of the project (may include a wide variety of disciplines such as health educators, social scientists, engineers).
- Develops **applied action** components and a proactive approach, prevention/intervention, including pollution prevention and action to reduce exposures.
- Addresses issues of **institutional change** (e.g., participation of all partners at all levels in the institution, the lack of people of color in research institutions, the need to bring in young people, need to recruit more potential scientists from communities).
- Applies systemic and strategic intervention methods, which include behavioral change from institutions (e.g., government and corporations) as well as individuals, the development and enforcement of standards, policy change, change in methods and levels of service delivery, and education and community organizing.
- Ensures that ownership of data and methods of dissemination are considered collaboratively.
- Examines the potential and actual impact of intervention.
- Develops new evaluation methodologies that broaden the definition of terms of success.

- Provides sustainable community involvement that leaves behind skills, relationships, services, systems of surveillance and data collection, and analysis in the community.
- Builds relationships with communities that offer new possibilities for research and new ethical questions to be addressed.



V. SPECIFIC RECOMMENDATIONS TO THE NIEHS

Continue and expand Environmental Justice and Community-Based Prevention/Intervention Research Programs with the following improvements:

Environmental Justice:

- Majority of funding is allocated to the community-based organization, unless otherwise requested. This is often the case in existing EJ grants.
- Community-based organization serves as Principal Investigator, unless otherwise requested. This is the case in the majority of EJ grants.
- Participatory research is a mandatory component and includes training, documentation/evaluation and an action-oriented outcome.
- Participants associate more strongly with NIEHS Centers.

Community Based Prevention/Intervention Research:

- More effective community participation with community-based organizations as meaningful partners in proposals, as is the case with NIEHS-supported CBPIR grants.
- Community-based members that wish to be Principal Investigators should be encouraged, with the realization that these are scientific research projects, not education or communication grants.
- Community participation in the application review process.

Additional research programs should be developed to address:

- Community-based risk assessment.
- Training of health care providers in environmental public health.

- Interactions among poverty, pollution, and health status.
- Popular epidemiology.
- Methodology of community-driven research.
- Effectiveness of the research collaboration model.

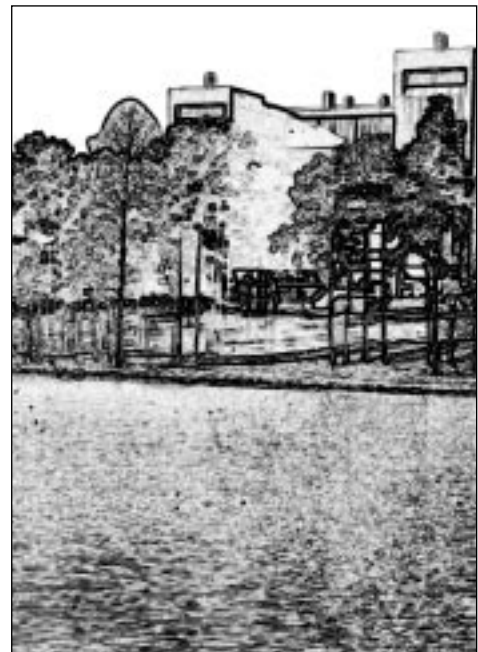
Facilitate communication between researchers and communities:

- Help create ways for communities to network directly and share what they have learned with each other.
- Provide technical assistance to researchers and communities in the application process.
- NIEHS Centers may be an appropriate site to facilitate these interactions.

Distribute planning grants of \$50-\$100K to precede project grants:

- Provide cross training for scientists and community members on the scientific process, grant writing, cultural sensitivity etc.
- Establish collaborative relationship between partners that is well documented in project proposal.
- Produce a community description and preliminary data for inclusion in project proposal.
- Identify research goals and evaluation/assessment criteria.
- Establish stronger, more rigorous link between environmental exposure and health status in a given community.

Advocate the collaborative research model to other NIH Institutes and government agencies.



CONCLUSION

The NIEHS grantee meeting served as a forum to build relationships and invited partners to collaboratively assess how research goals are being met. Community partners began to speak strongly to fulfill their role as full colleagues and contributors in the research process. They defined their own expertise in organizing and building community capacity to collaborate, study, understand and build the necessary support to accomplish intervention for the health and future of their communities. Not only do communities want to contribute what they know to advance scientific understanding, but they also want scientifically guided action.

While community members are becoming versed in scientific issues, more scientists are also learning to understand community issues. Both partners are growing more comfortable with stepping into each other's shoes. Grantees reiterated the inherent complexity of EJ research and the time it requires to consider all factors: multiple toxicity, synergistic effects, compromised health status, etc. Participants used a dialogue and synthesis process to focus on these issues, and then addressed questions of research design and process that are critical to "Community-Driven Research."

Community partners particularly advocate a more systematic process in the area of research design. Components of a planning process would include a more proactive matching of communities to scientists, more discussion on the allocation of resources, and more training for communities in basic scientific methods. Participants also identified the need for methods to help scientists understand and value community input.

NIEHS may yet see surprising results from their investment, and may, in the course of bringing grantees together from diverse backgrounds, develop a new kind of multidisciplinary professional collaboration that recognizes the value of all partners. This community of partners could develop the political force necessary to make science more accountable,

responsive and useful to the very constituents who need it most.

The annual grantee meeting, as well as the peer review processes that preceded it, contributed to new understanding and awareness among diverse partners. But as grantees noted, the development of new relationships takes a long time and great commitment. Without tangible investment in trust building, the development of new skills and modes of collaboration, and time, the full potential of accomplishment may fade before it becomes evident. Foundation and federal support is essential, as are results.

Participants agreed to work together to assure that NIEHS continues the EJ and CBPIR programs, investing more in building relationships and learning that will improve science and environmental health in communities suffering from environmental injustice. On a frontier precisely where the skills of scientists, health care providers and community members are all essential to solving the problems of pollution, inequity and poor health, the pioneering NIEHS programs are providing national leadership.



Appendix A: Notes from 10/28/97 Break-out Group on Developing a Community Research Agenda

Brain-stormed List Organized by Subject Area

Research Needs

Need scientists to help map and define community identified problems—from that, multiple research questions emerge, e.g.,

- Cumulative impact of multiple pollutants
- Synergistic (how pollutants interact) effect of pollutants
- Effect of pollutants on small population groups
- Interaction of multiple community issues: geography, income, etc.
- Impacts of low level exposures

Interdisciplinary team of researchers is necessary to:

- Measure the impact of environmental problems by different kinds of indicators: social, medical, etc.
- Examine barriers to community involvement: residents are dealing with multiple issues
- Expand definition of how communities are impacted by environmental pollution through community input.
- Offer alternatives to risk assessment process.
- Define limits of science in assessing community environmental health problems.
- Establish research that is conducted by the community itself.
- Reduce the lack of a variety of data: e.g., hospitals collect data in such a way that makes it difficult for communities to use for research purposes.

RESOURCE ISSUES

Grant Processes

Eligibility

- Environmental Justice programs can help fill the gap between community research needs and basic research projects.
- Policy changes in funding programs are necessary to allow for interaction between multiple issues.
- RFAs that go directly to the community, such as NIEHS EJ grants, and training/support for the community to provide its own principal investigator.
- Funded proposals should include a plan for what resources will be left for the community.
- Need support for descriptive research.
- Grant review processes that allow communities a chance to further develop a grant if it's not sufficient at first review, such as those used at NIH.

Developmental Resources

- Need time for dialogue with interdisciplinary team before research projects begin. (Pre-research development funds to do this.)
- Social scientists (e.g., anthropologists, sociologists) involved from the beginning to help residents frame questions that biomedical scientists understand.
- Training in order to understand basic terminology and concepts before grants are prepared (time, space, and budget allocation).
- Training to translate needs into marketable strategies (e.g., cost of health care related to exposure to pollution.)
- Develop model whereby communities can calculate their financial needs in advance of grants being written.

- Foundations to fund technical assistance, organizing, organizational development, etc. in order to establish effective collaborations.

Project Models

- Community needs to be respected as an equal partner, as is the case in NIEHS EJ grants.
- Develop ways for environmentally impacted communities to communicate directly with each other.
- Sufficient time on grants to collect necessary data.
- Models in which collaborative research can also serve as an education tool.
- Projects need to work with the total community, not just officially recognized leaders.
- Need to define responsibility of partners (community, scientists, and health care providers) within grants and provide money for each to meet its responsibilities.
- Equipment purchased for projects should stay within the community once project is over.
- Need to examine these projects before they are over to see what activities can be continued after the grant is gone, what resources are being left for the community (e.g., impact on school curriculum which continues).
- Need for financial and personnel (e.g., social scientists) resources necessary for measuring impact of environmental problems by different kinds of indicators: social, medical, etc.

Community Resources

- Need to develop strategies that bring more resources into the community.
- Pro-active projects: Develop local research agendas and then go to public and private foundations.

- There is a contradiction when community driven agenda is funded by institutions outside the community.
- Need for sustainable resources from within the community.
- Community needs to be continuing the process of developing its own agenda for social action oriented research.



